

UNDERSTANDING AND RESPONDING TO DIFFICULT BEHAVIORS

Changes in behavior are often associated with dementing illnesses such as Alzheimer's disease. Increased restlessness, agitation, wandering, abrupt changes in mood, inappropriate responses to social situations, repeating the same question over and over, wanting to go home--these are behaviors which caregivers may be called upon to manage.

Each victim of dementing illness is unique. The presence of behaviors such as these, and the intensity of the behaviors, will vary greatly from patient to patient. It is important to realize that the behavior is a manifestation of the illness, and is therefore something beyond the patient's control.

There are many reasons why a difficult behavior may occur. The most common reasons have to do with:

- * causes related to the person's physical and emotional health
- * causes related to the environment
- * causes related to the task
- * causes related to communication

Since we cannot expect the victim of Alzheimer's disease to change his behavior, we must find ways to accommodate and work with behaviors that are difficult for us.

Caregivers are encouraged to problem solve in the following ways:

- ** When does the problem occur? Were there precipitating factors? What was happening right before the behavior occurred?
- ** Was the behavior brought about by one of the reasons listed above?
- ** What emotions did the patient exhibit before the behavior? During the behavior? Can you respond to the emotion rather than the behavior?
- ** Develop a list of responses to the behavior. Ask other caregivers to review the list.
- ** BE FLEXIBLE!! What works for one occasion may not work for another. What works for one caregiver may not work for another. Don't be upset if your strategy is not successful, or has limited success.

Resources available from Alzheimer's Associations across the State:

Understanding Difficult Behaviors, by Anne Robinson, Beth Spencer and Laurie White. Geriatric Education Center of Michigan, 1991.

The 36 Hour Day: A Family Guide to Caring for Persons with Alzheimer's Disease, Related Dementing Illnesses, and Memory Loss in Later Life, by Nancy mace and Peter Rabins. John Hopkins University Press, Baltimore, 1991.

Alzheimer's: A Caregiver's Guide and Sourcebook, by Howard Gruetzner. John Wiley & Sons, 1988.

Care of Alzheimer's Patients: A Manual for Nursing Home Staff, by Lisa P Gwyther. American Health Care Association and ADRDA, Inc., 1975.

Videos in the Caregiver Series: "Safety First", "Managing Difficult Behavior," "Meeting Daily Challenges", "Caring for the Caregiver," "Communicating".

SPECIAL MANAGEMENT ISSUES

(Excerpts from Caring for the Memory Impaired: Strategies and Techniques That Work, by Janet C. Sawyer, Edna Ballard and Pamela Utrey. NC Department of Human Resources, Division of Aging, Revised, 1990.)

Orientation to time/place/person

Problem: The patient is confused or mistaken about the time of day or year (i.e. thinking mother is still alive, or that it's time for lunch when she just ate lunch); about where she is (she thinks she's in the house she grew up in, or she can't find her way around the nursing home and keeps "losing" the dining room, the bedroom, or the bathroom); about who's who (she may call her daughter her mother, or think that you are her child, or not recognize her husband of 50 years).

Causes: Patient has limited recollection--or no recollection at all--of people or places or events due to memory loss. This may be compounded by prior vision or hearing and by misinterpreting the sensory information that comes to him.

What you can do:

- * Calmly identify time, place, or person to the patient.
- * If the patient insists that her perception is correct and yours is wrong, don't argue! For example, if the patient insists that she needs to go home to take care of her children (she is disoriented to time and place), you might say, "I understand how much you love your children. Do you remember how you used to cook mashed potatoes for me every night?"--effectively distracting her while validating her roles as a mother and caretaker.
- * Visual cues--name tags, door markers, "landmarks" such as pieces of furniture or changes in the decor--can help orient some patients if they are pointed out and consistently used.
- * If your patient has trouble remembering the nature of relationships, you can support him by saying, "Our grandson, John, is coming to see you," or "Your neighbor, Fran, is here to take you out to lunch." Whenever possible, assist him in recognizing the person who is significant to him.
- * The same goes for orientation to time and place. Your "introduction" helps the patient know where he is and what he's supposed to do. ("Let's go to the kitchen. It's almost time for lunch." "Your friend, Mark, is here to take you to the barber shop. You have an appointment at 2:30 this afternoon.")

Combativeness and Catastrophic Reactions

"When you're upset, they're upset. I've learned I have to keep calm when my husband gets angry about something that I can't do anything about."

Problem: Patient overreacts, sometimes over minor things, and quickly becomes unmanageable or combative.

Causes: Catastrophic reactions may be caused by something external in the environment--the sound of the television, over stimulation at mealtime, being touched from behind when it isn't expected--or by the patient's own frustration with his limited abilities (for instance, not being able to button a shirt, not recognizing a face that seems familiar, not knowing

where he is or what he's supposed to do there). The patient may misunderstand stimuli or may misinterpret what is going on around him. He may strike out in his fear or confusion.

What you can do:

- * Look for the cause of the patient's immediate acute confusion.
- * Do not argue with the patient--turn him in another direction, walk him into another part of the room, give him something to hold.
- * Reassure the patient that you know he's upset and that you'll take care of the problem.
- * Stay calm yourself!!
- * Remove objects which may be dangerous to the patient during catastrophic reactions.
- * The best approach for managing catastrophic reactions is to diffuse them before they happen! Look for excessive agitation, tenseness, or unusual facial expressions or gestures. These often give you non-verbal clues about what is bothering the patient.
- * If you feel that either the patient or you are in danger, get help immediately.

Suspiciousness/Paranoia

Problem: Patient mistrusts you or others. Patient may believe that something is true which she is actually imagining.

Causes: Because patient mistrusts her own memory and knows that she may be making mistakes, she may be fearful of trusting others to take care of her affairs the way she would like. She may become fixated on ideas that have no basis in reality: the nurses are trying to poison her; her son is stealing all her money; the man in the television is talking to her; the man who says he's her husband is not really her husband although he looks like him. Her poor memory and her inability to make sense of the environment, of events, or of situations exacerbate the problem.

What you can do:

- * Respect the patient's view of reality without "buying into it." ("I know you think that there's something wrong with your applesauce.")
- * Acknowledge her feelings of fearfulness, mistrust, etc., and offer to help her with the immediate problem. ("I certainly wouldn't want anything to happen to you. I will look
- * Don't react defensively to her accusations. ("How could you possibly think that I would want to poison you?") Don't take things personally!!
- * Remain calm. Reassure the patient of your concern and desire to help.
- * Try distraction--take the patient to another location, give her something to hold or look at, or spend a few moments talking about something else.
- * Even if the patient cannot be distracted from her incorrect beliefs, she will subconsciously respond to your concern and your interest in her.

"I used to have my feelings hurt all the time by things mom would say to me. Now I know she doesn't really mean it--it's just the Alzheimer's talking."

Hallucinations

Problem: Patient sees or hears things that are not there.

Causes: Vision or hearing problems, misinterpretation of the environment, physical problems (such as pain, fever), dehydration, nutritional, or psychosis related problems.

What you can do:

- * Don't argue or try to reason with the patient. (Remember, the experience is real to them).
- * Reassure, if upset; distract if you can. "I will stay with you," or "Let's walk down to
- * Reduce clutter so patient can see better and have fewer stimuli to deal with.
- * Make sure patient can see and hear adequately (be aware of glare, reflections, noise, etc.).
- * Respond to the patient's feeling about the hallucination--"That must be frightening for you." This reassures the patient that you understand her fear and that you care about her feelings.
- * Monitor medications which might contribute to the patient's tendency to hallucinate. Inform the physician about tendency to hallucinate.

Delusions

Problems: Patient has a fixed belief about something with no basis in truth: i.e., believing that someone is trying to harm him, steal from him, spy on him.

Causes: May be caused by any number of factors. The patient may be confused about the intent of others, may misunderstand actions, may be compensating for forgetfulness by misinterpreting the reality of the situation, may be having adverse reaction to medication.

What you can do:

- * Don't argue with the patient.
- * Try to reassure the patient if he is agitated or anxious.
- * Inform the physician of the delusion.
- * If the delusion is harmful or interferes with good care (i.e., the patient refuses to eat and thinks the food is poisoned, and distractions or reassurances don't work), report this to the physician. Medications may be indicated to reduce the delusional behavior.
- * Sometimes the delusion is harmless (for instance, the patient seems to enjoy an imaginary friend or pet). In this case, support the patient in his feelings without "buying into" the delusion.

"One of the hardest things for me was having my mom tell everyone that I was taking her money. She couldn't pay her own bills, and she was always accusing me of stealing from her. I knew I had to take care of her finances, but I couldn't convince her that I was acting in her best interest. She worried about money for a long time. Even though I never convinced her, I had to accept the fact that I was doing the best I could for her, and go on from there."

Anxiety/Agitation

Problem: Patient becomes extremely upset or concerned about her safety or well-being and may react in a number of ways, including withdrawing, striking out, pacing, exhibiting uncooperative behavior, crying, using excessive or abusive language.

Causes: Fear of not being able to perform a task or activity; too much stimulation; fatigue; confusion; embarrassment over losses.

What you can do:

- * Stay calm even in the face of extreme agitation.
- * Reduce activity or demand on the patient.
- * Remember that clutter, noise, too many people can all be upsetting or threatening to the AD patient.
- * Remove patient from the environment and take her to a quiet place.
- * Leave the patient alone and come back later.
- * Provide structure, routine, and safe environment.
- * The patient will function best in a predictable routine. Avoid changes in her environment or in her schedule unless planned out in advance.

“With kids and the schedules, we were always coming and going. I learned that we needed to keep a predictable routine that Mom could get used to. It was hard for us to do this, but it really helped Mom, so I guess it helped us out, too!”

Sleep

Problem Patient has trouble falling or staying asleep; gets up frequently through the night (often wanders, gets lost, rummages about).

Causes: Older adults have less efficient sleep, resulting in less “deep sleep” and in more frequent periods of arousal. Patient may need to go to the bathroom; may be confused about the time to get up; may be fearful and need comforting or reassuring. Many Alzheimer’s patients experience extended periods of sleeplessness and restlessness, going for days or weeks with very little sleep.

What you can do:

- * Provide sufficient exercise, activity and fresh air during the day.
 - * Take the patient to the bathroom before he retires.
 - * Provide a bedside commode if incontinence is a problem and the patient has difficulty finding his way to and from the bathroom.
 - * Tell the patient, “Go back to bed. It’s time to sleep.”
 - * Let the patient pace a while if he is very restless.
 - * Provide a favorite “security blanket”.
 - * Give the patient a snack. Hunger may be keeping him awake.
 - * Give the patient warm milk or decaffeinated tea or coffee.
 - * Monitor medicines which may cause the patient to sleep too much during the daytime.
- Ask the physician if the schedule can be changed to ensure longer sleep at night.

believe it the first time Jim yelled at me. He never raised his voice before he got sick. We both cried afterwards, but I knew that he was changing and that I had to start looking to my friends for the support and love that he had once provided.”

Sundowning

Problem Patient becomes confused, restless, agitated in late afternoon or evening.

Causes: Patient becomes tired, and coping ability is sapped; patient may have difficulty in adjusting to a change in routine (such as increase or decrease in activity level of people around him, children coming home from school, shift change in a nursing home). Patient may misinterpret environment changes such as noises, shadows, activity. Researchers suggest that there may be other causes of sundowning which we don't fully understand at this time.

What you can do

* Turn on the lights prior to twilight.

sundowns' may be helpful in preventing excessive agitation during the late afternoon.

- * Provide a safe place to pace or rummage, and be sure that the patient has sufficient rest periods during the day.
- * Provide security with favorite items--pictures of family or the old homeplace, a doll, a stuffed animal, a pet.
- * Reassure the patient.
- * Try giving a snack or something to drink.
- * Sometimes patients respond well to music.

"Late afternoon was the worst time for us..."

Mealtime Problems

"Dad kept losing weight, even when he ate everything in sight. We checked with the doctor and gave him supplements, but nothing seemed to help. For some reason the body didn't metabolize nutrients well. The dietitian told us that some Alzheimer patients go through that stage and then they usually stabilize."

Problem: Patient can no longer handle utensils; has increased or decreased appetite; eats inappropriate things.

Causes: Patient may have forgotten how to use utensils or how to actually begin the process. You may need to demonstrate or begin the motion for her. Patient can't make the connection between eating and the sensation of being hungry, and has lost good judgment concerning what is appropriate to eat and when to eat. Too many food choices may confuse the patient and she may become "stuck", in which case she may play with her food or wander away from the table. Patient may have difficulty chewing or swallowing.

What you can do.

- * Provide quiet, uncluttered places to eat.
- * Limit food choices and amount of stimulation on the table and in the room.
- * Demonstrate or give directions on getting started. Remain friendly, calm, unhurried.
- * Present foods according to the patient's ability--finger foods when he is no longer able to handle utensils, pureed foods when there are chewing or swallowing difficulties.
- * Do not assume that an AD patient is not hungry if he does not eat his meal. He may not be able to associate being hungry with the food that is in front of him.
- * Make use of assistive devices such as suction plates, large-handled utensils.
- * If the patient consistently refuses to eat, check for poorly fitting dentures or sore gums.
- * Allow enough time for the patient to complete a meal. Remember, the patient's slow reaction time may require a long time to finish the meal.
- * Don't force an agitated patient to eat. Be sure patient sits up for 20 minutes after eating to avoid choking. Also, be sure that the patient is not holding food in his mouth.

Difficulty with Bathing

“Mom would always say she’d just taken a bath, and that she’d take another one tomorrow. She smelled awful, and she never changed her clothes. She used to be so neat and tidy...”

Problem: Patient refuses to bathe, and becomes angry, agitated or violent in his refusal to take a bath.

Causes: Patient may feel overwhelmed by the bathing process. The different steps necessary to take a bath may confuse him. The patient may be unable to follow directions, or to understand what to do even when being assisted in such a personal, intimate task. A lack of privacy may heighten these feelings. The patient may not understand why bathing is necessary, and may have a diminished sense of personal hygiene. Patient may fear the water, or other noises or sensations associated with bathing. Depression associated with dementia may cause the patient to have difficulty in participating in any activity.

What you can do:

- * Follow the same routine each time you give the patient a bath.
- * Learn the patient’s bath routine. Does he prefer a bath or a shower? When does he like to take his bath?
- * In preparation for the bath, gather everything you will need ahead of time. This may reduce the anxiety level for your patient.
- * Do not ask the patient, “Would you like to take a bath?” The answer invariably is “No!” Instead, say something like, “It’s time for your bath. Take my arm and we’ll walk
- * If the patient is agitated, approach calmly. Return later if you are not successful.
- * Respect the patient’s need for privacy, and draw the curtain or close the door if he can be left without direct supervision.
- * Respect the reason for resistance. For example, the patient may be angry or frustrated over not being able to do the job himself.
- * Model how to do the task. Simplify your instructions and support the patient in doing as much as he can for himself.
- * Monitor water level and temperature carefully. The patient may have lost the ability to react to dangerously hot water.
- * The patient does not need a complete bath everyday. A sponge bath may be sufficient. It is important, however, to wash and dry thoroughly the genital area to prevent rashes or skin breakdown, especially if the patient is incontinent.
- * If the patient also resists washing hair, the bath process may be easier if the two are separated.

“We finally solved the problem of Mom’s not changing clothes by buying two of everything. That way she could wear one while we washed the other. She did best in sweat suits and in dresses that could slip on. Button and close-fitting dresses were more of a problem for her.”

Toileting and Incontinence

Problem: Patient has difficulty finding or using the bathroom; patient is incontinent of bowel or bladder.

Causes: In earlier stages, patient may forget where the bathroom is, may forget how to manage undressing, or may have difficulty unfastening clothing in time to avoid having an accident. In later stages, patient may be unaware of the urge to void and how to respond appropriately.

What you can do:

- * Train yourself to respond to the patient's particular bowel and bladder needs.
- * Regular trips to the toilet, with as much assistance with clothing as necessary, will help the patient to avoid the discomfort and distress of incontinence.
- * Try clear, concise signs ("BATHROOM") which can be read easily from a wheelchair or with poor eyesight.
- * Watch for increased agitation, fidgeting, or calling out which might indicate a need to use the bathroom.
- * If the patient retains some independence in toileting, make certain that the fastenings on his clothes are easy to manipulate and that he heads for the bathroom in plenty of time to avoid an accident.
- * In the later stages, when a patient may not understand what he is to do in the bathroom, it is important to monitor him regularly to make sure he is clean and dry.

Resources to Help Families With Problems Caused by Incontinence

Staying Dry: A Practical Guide to Bladder Control, by Kathryn L. Burgio, Lynnette Pearce, and Angelo J. Lucco. The John Hopkins University Press, 701 West 40th St., Baltimore, Maryland, 21211-2190. Paperback, 169 pp. \$12.95.

Help for Incontinent People (HIP) has published a resource guide to assist people in finding the types of products that are most helpful for their particular problems. To receive information, mail a stamped, self-addressed business-size envelope with your letter to:

HIP
PO BOX 544
Union, South Carolina 29379
1-800-579-7900

The Simon Foundation also provides information about incontinence. To receive information, mail a stamped, self-addressed business-sized envelope with your letter to:

The Simon Foundation
PO BOX 835

Wilmette, Illinois 60091
1-800-23-SIMON

There are also a number of mail-order companies which deliver incontinent supplies to the home. National Incontinent Supplies Inc., PO Box 95, St. Peters, Missouri, 63376 (1-800-228-8718) offers free home delivery.

WANDERING

Wandering behavior is one of the most risky, frightening behaviors with which caregivers must deal. Not every patient wanders, but the potential for getting lost and wandering away poses serious risks to the patient. For that reason, every caregiver should take some preliminary precautions:

- * Have a current photograph of the patient.
- * Have information about the patient which describes hair color, identifying marks, medical condition, color of eyes, complexion, blood type, jewelry which is customarily worn, use of glasses and/or hearing aids.
- * Collect the patient's scent and store it. (While wearing rubber gloves, take a cotton ball and stroke the patient's skin to collect his scent. Store the cotton in a tightly closed plastic bag).
- * Inform neighbors, local police, firemen, and others of the patient's condition. Keep a list of their telephone numbers handy.
- * Consider using a medic-alert type bracelet or locket that includes the patient's name, telephone number, memory problem and medical condition. Consider also marking dentures, eyeglasses, keys, and shoes with identifying information.

To safety proof a home:

- * Place locks out of vision or out of reach. Since dementia victims have difficulty accomplishing tasks that require several steps, use several locks of different types--hook & eye, bolt, doorknob lock. Consider a child proof door knob, or a buzzer system that rings when the door is opened.
- * Put hedges or fences around your patio or yard.
- * Put locks on gates.
- * Place a pressure-sensitive mat at the door or person's bedside. Use "Baby monitors" (such as Fischer-Price) to monitor activity in another room.
- * Camouflage some doors with a screen or curtain, or put a two-foot square of a dark color in front of the door knob.
- * Use a safety gate across doors or at the top or bottom of stairs.

Other helpful suggestions are available in Understanding Difficult Behaviors, by Robinson, Spencer, and White. Available from the Alzheimer's Association-- Triad NC Chapter.

ADDITIONAL TRIAD AREA RESOURCES

Alamance County: Care Trak bracelets and belts are available through the Alamance County Rescue Squad. Contact Bennie Brooks, 919-228-1312, ext. 245. The patient wears a miniature transmitter on the wrist or in a belt. The transmitter gives a signal that

can be located up to a mile in distance. Signals are tracked by a mobile unit, which is kept at the Alamance County Rescue Unit. Cost: based on need.

Forsyth County: Care Trak bracelets and belts (see description above) are available through the Alzheimer's Association--Triad NC Chapter office. Call 919-722-0811. The mobile monitor is housed with the Forsyth County Special Operations Response Team (SORT). Cost: based on need.

Guilford County: Project Help bracelets are available through the Guilford Co. Emergency Services. The patient wears a bracelet with an identifying number. Identifying information is kept with Guilford County Emergency Services. Contact Susan Shields at 919-373-7565. Cost: free.